

# Women's Experiences of Living with Burning Mouth Syndrome: An Interpretative Phenomenological Analysis



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## Abstract

**Objective:** Patients with Burning Mouth Syndrome (BMS) report a lower quality of life in comparison to a healthy population. However, qualitative studies exploring patients' experience of living with BMS has been limited. This Interpretative Phenomenological analysis aims to understand the individuals' experience of living with BMS and how this impacts on 'self'.

**Methods:** Four women, diagnosed with BMS, were interviewed using a semi-structured interview guide.

**Results:** From the analysis four master themes were identified: (1) the doubting self; (2) the hidden self; (3) BMS as an intrusion; (4) diagnosis as a turning point.

**Conclusions:** Through the process of diagnosis, treatment and management of the condition the women appear to reclaim their 'autonomous self' from the former 'fragmented sense of self' which existed prior to BMS diagnosis.

## Precis

To understanding women's experience of living with a diagnosis of Burning Mouth Syndrome and the impact the syndrome has on 'self' and their quality of life.

**Keywords:** Burning mouth syndrome; Dentistry; Interpretative phenomenological analysis; Chronic pain disorder

## Introduction

Burning Mouth Syndrome (BMS) is a chronic pain disorder with distressing symptoms. It is characterized by an absence of organic disease, yet a persistent burning and/or itching sensation in the oral cavity [1]. It mainly affects the tip and the anterior two-thirds of the tongue, although other areas, including the hard palate, lips and alveolar ridges, buccal mucosa and the floor of the mouth, may also be affected [2]. Pain is intense and the symptoms tend to last a minimum of 4-6 months, and may be relieved by consuming food. BMS can also be accompanied by Dysgeusia (an alteration in taste) and subjective Xerostomia, also known as dry mouth [3].

These painful systems can have a severely debilitating effect on the individual's day-to-day functioning.

Burning Mouth Syndrome is a relatively common condition. However, its precise prevalence has been debated. Presently,

studies detailing its prevalence have not been carried out in Ireland, although a number of European studies have been conducted. Tammiala-Salonen et al. [4] found an exceptionally high rate (15%) of BMS symptoms in a Finnish general adult population. The longitudinal study represented a large sample (237 females and 194 males); however, half of the patients had visible oral mucosal lesions which may, or may not, have been associated with BMS, and may have accounted for the high percentage. A cross-sectional analysis by Bergdahl & Bergdahl's [5] found a high incidence (3.7%) of BMS. Although this Swedish study involved a large sample size (669 men and 758 women), it was not representative of a general population as the sample participants were randomly selected from Public Dental Health Service registers. In contrast, an earlier study by Bergdahl & Anneroth [6] showed a much smaller prevalence of BMS, in this case 0.7% of the general population. This variability may have

arisen because the earlier study did not include the burning sensation of the oral mucosa in their BMS criteria.

Scala et al. [7] claim that around the world BMS was more prevalent than previously estimated. In support of this, they referred to a representative survey in which 1.3 million Americans were estimated to be affected by BMS [8].

BMS also appears to affect a particular age group and gender. Burning Mouth Syndrome occurs more often in older adults. Bergdahl & Bergdahl's [5] cross-sectional study reported an increase of 0.6% of Burning Mouth Symptoms in the 30-39 age group as compared to 12.2% in an older age group. This is consistent with other studies [9,10] which reported an age range of 38 to 78 years. Furthermore, up to 90% of female patients with BMS are peri-menopausal women, with typical onset of BMS from 3 years peri- to 12 years post the menopause. Women are 2.5 to 7 times more commonly affected than men, according to a recent case-control study based on patient records [11]. This predisposition of women is also reflected in Hakeberg et al. [12] earlier study which found that women were more predisposed to BMS. Therefore, the most commonly affected individuals are older and menopausal women. However, the incidence of BMS in the general population, and its prevalence among older women, depends on how accurately Burning Mouth Syndrome is defined.

Burning Mouth Syndrome has been defined in a number of ways. The Headache Classification subcommittee of the International Headache Society defined BMS as 'a burning sensation for which no dental or medical cause can be found' [13]. The International Association for the Study of Pain provides a slight alteration to this, defining BMS as 'a distinctive nosological entity characterized by unremitting oral burning or similar pain in the absence of detectable mucosal changes' [14]. Both definitions recognize that BMS is characterized by a burning pain, with no visible or otherwise known dental or medical cause. Both definitions also maintain that the stinging and burning sensation may be present in other areas of the mouth other than the tongue and that oral dryness and an altered sense of taste may be present. BMS is also classified as a chronic pain disorder by the International Association for the Study of Pain [14] given that BMS's painful persistent symptoms that exist for more than six months.

Bio psychosocial models have been generally used to explore the factors that interact in the development of Chronic Pain Disorder, which include BMS. One such model is that of Carlsson & Jern's [15] systems-oriented, multi-causality paradigm where psychological, social, and physiological factors interact with each other to generate psychological, social, and somatic variations over time. This model shows that psychological factors (life events relating to psychology or to an individual's psychological predisposition), an individual's social relationships and interactions with others, and his/her physiological and biological factors can manifest in the development of chronic pain. This is comparable to the psychobiological model by Dworkin et al. [16]

ecological-dynamic theory of chronic pain. Both models illustrate that chronic pain disorders, including Burning Mouth Syndrome, can be a complex manifestation of a number of interacting factors.

Recent research has started to examine living with chronic pain and its impact on the 'self'. Pincus & Morley [17] hypothesized that the experience of chronic pain relates to the degree to which pain, self, and illness become enmeshed. There have been some qualitative studies, especially in the area of chronic low back pain, that have explored how chronic illness impacts on 'self' [18,19]. However, little attention has been paid to the nature of the relationship between Burning Mouth Syndrome and its impact on 'self'.

The interaction of various factors in the development of Burning Mouth Syndrome has not been overlooked. Pokupec-Gruden et al. [20] claim that Burning Mouth Symptoms are a product of local factors (biological factors i.e. candidosis, gingival and oral conditions), systemic factors (factors which cause the whole body to be affected i.e. drug and alcohol use, immunological and hormonal disturbances) and psychogenic factors (including depression, anxiety and various psychological disturbances). Other factors that have been shown to interact in the development of BMS are gender, age (peri-and post-menopause), and various conditions such as Parkinson's disease, as well as chronic medical conditions, including gastrointestinal and urogenital diseases [1].

One of the risk factors that has been a central focus in psychological and psychiatric research is psychogenic factors. Rojo et al. [21] in their case-controlled study assessed 49 patients with Burning Mouth Syndrome, using a psychiatric interview and a self-administered psychopathologic questionnaire (SCL-90). The BMS group presented significantly more clinical manifestations of anxiety and depression, as well as obsessive symptoms, summarization, and hostility. Personality disorders have also been shown to be linked to BMS, and to affect 86% of sufferers as compared to 24% of the control group, with significant tendency to 'Cluster A' personality disorders [22]. Recently, a cross-sectional study by de Souza et al. [23] showed that BMS patients have a significantly higher occurrence of past or present major depressive disorders, general anxiety disorders, hypochondria, and cancerophobia. The researchers claim that there is a relationship between psychogenic factors and BMS. However, there remains a dispute about the relationship between psychiatric illness and BMS, and many researchers and clinicians consider psychiatric disease to be a secondary factor of BMS, given that any long-term illness can cause psychological disturbance [24-26]. BMS encompasses a variety of treatment methods, with a medical model of treatment taking precedence over the others. However, in relation to BMS psychological treatments have shown promise. However, present research is sparse [27,28].

Recent studies have investigated the effect of BMS on the individuals' quality of life. The World Health Organization [29] defines Quality of Life (QoL) as 'an individual's perception of their position in life, in the context of the culture and value systems

in which they live, and in relation to their goals, expectations, standards and concerns.' Some studies that focus on BMS have shown that it has a negative effect on patients' Quality of Life in regards to vitality, physical functioning, bodily pain, general health perceptions, physical, emotional and social role functioning, and mental health [24,30,31]. These mixed method studies provide an insight into the impact of BMS on the quality of life, but do not explore in-depth the individual's experience of living with BMS and its impact on 'self'. Qualitative research in the area of BMS is exceptionally sparse with only one grounded theory study by Hakeberg et al. [32] which offers an in-depth understanding of BMS as a psychological discomfort which the women needed to talk about. The women also experienced psychosocial overload, existential worry in response to a psychological stress.

### Aim

To understand women's individual experiences of BMS by focusing on the impact the syndrome has on 'self' and on their life world.

### Methodology

A qualitative research design was undertaken given that the researchers were concerned with the quality and texture of people's experience and the meanings attributed to events and situations by the participants themselves [33]. Qualitative research provides rich descriptions [34] while also capturing the individual's perspective and their individuality, which is pertinent to exploring Burning Mouth Syndrome.

Interpretative Phenomenological Analysis was used in this research as it allows for exploration of and reflection on individual patients' BMS experiences. Semi-structured interviewing was chosen for this research as this form of interviewing facilitates the interviewer and interviewee to engage in a flexible dialogue where questions can be altered in light of the interviewee's responses, and the interviewer can probe significant aspects that arise [35].

### Method

**Participants:** Four women, diagnosed with BMS, and who were currently accessing a city dental hospital for treatment participated in the study. The women were between the ages of 45-60yrs. and were Irish Caucasian and from a working-class background. The participants represented a homogenous, purposive sample [34]. All participants were recruited through a 'gatekeeper', a consultant oral medicine physician, who provides treatment and support for the patients.

**Procedure:** A semi-structured interview schedule was developed. It centered on three main themes: the participant's individual experience of BMS and how it affected their quality of life; management of the condition and patients' coping skills; and BMS's effect on their sense of self. All interviews were face-to-face, and conducted in a familiar clinical setting lasting approx. 1hour. All interviews were digitally recorded and transcribed verbatim.

Any identifying information was removed from the transcripts and pseudonyms were used.

**Data analysis:** Data was analyzed using Smith and Osborn's [34] four-stage guidelines for Interpretative Phenomenological Analysis (IPA). IPA has been specifically developed within health psychology to understand the 'lived' experience of the patients, and offers a systematic approach to achieving this [35].

The first step involved reading and re-reading each transcript in order to become familiar with the data. The second step involved identifying emerging themes. Here, the initial notes were converted into short phrases which encapsulated clearly what was being said in the interview but in a more interpretative manner. The third step involved searching for interconnecting themes. The fourth step was to produce a table of themes for each participant, searching for differences and similarities and then creating a master table of the most significant themes for the participants.

**Ethical approval:** Ethical approval for this study was granted by an internal university ethics review committee.

### Results

Interpretative phenomenological analysis revealed a number of master themes and sub-themes from the transcripts: 'the doubting self,' 'the hidden self,' 'BMS as an intrusion,' and 'diagnosis as a turning point.' Within each of these master themes, sub-themes were identified.

#### The doubting self

The doubting self is representative of the women's inner struggle as they become confronted with their developing symptoms and begin to doubt and question themselves at one point or another. This doubt was particularly evident in the early stages of BMS and was attributed to the lack of knowledge they had about it. This lack of definitive knowledge of the condition led the women to question their symptoms, and eventually to question their mental health. This doubt and uncertainty led to a diminished sense of self.

The developing symptoms of BMS led the majority of the women to become uncertain and to question the origin of their symptoms. This questioning was indicative of the fear and uncertainty associated with the mysterious symptoms they experienced.

For Alison, BMS transformed her from a woman who took her health for granted to someone beginning to doubt her sanity and health and, ultimately, the very essence of her identity. But you begin to question yourself, I think. Jesus what's wrong? like why am I feeling like this all the time...It was just, it was, "what is wrong with me?" (Alison).

Fiona began excessively thinking about her symptoms as she strove to seek answers. She expresses this doubting of self as a constant rumination, focusing on the symptoms of her distress

and the possible causes and consequences of burning mouth syndrome.

And sit down and just... you're just pondering on it. Just thinking about it all the time because it's just there all the time going on. (Phyl)

This rumination was linked to an onset of depressive symptoms as experienced by the majority of the participants. Phyl presented two conflicting sides of herself: one, confident that she isn't depressed, and the other recognizing that she is experiencing depression. This conveys an inner struggle, which she seems to resolve by describing symptoms synonymous with depression and thus indicating her depressive state.

It was definitely depression. And I used to be saying to myself I couldn't be depressed because what I was, I know I was depressed. I didn't want to be with anyone. I didn't want anyone around me, or anything. (Phyl)

Anna, in contrast, displayed an autonomous self that stoically accepted her condition and presented depression as an optional aspect of BMS.

I suppose you could go the other side of the coin and throw yourself down and spend the whole time complaining, but what's the point, you'd only depress yourself. There are just so many worse things you could have, you know, life-threatening or whatever. I can live with it and that's it. (Anna)

All women were concerned about their overall mental health at some point. However, the degree to which they questioned their mental health varied. The women described their doubts in over-simplistic, almost frivolous terms such as 'cracking up' and 'going mad' which indicated a somewhat detached view of their mental health, and may also have been an attempt to diffuse the seriousness of what they were acknowledging. Perhaps the women were somewhat distressed at their admission and the extent to which BMS did in fact affect them. This may be particularly true of Anna, as previously she had shown little acknowledgement of burning mouth syndrome's negative effect on her sense of self.

### Hidden self

The hidden sense of self is indicative of the 'real' or 'whole' self, becoming increasingly hidden away as a result of the symptoms experienced, whilst presenting a more socially acceptable self to the outside world. BMS diminished the self to a sub-self that exhibited a weakened sense of autonomy and independence. For Phyl, this manifested itself in a change in herself that she could not quite articulate. For her, any remnants of the former self were no longer recognized to the point that she didn't think of herself as 'normal.'

Well, one time I was there and all of a sudden I started feeling different to how I normally would feel. (Phyl)

Participants experienced grief and mourning at the need to hide their former self. This contributed to a loss of the women's

self-efficacy, or belief in self, and also their making sense of their own life. Phyl describes this grief vividly as she indicates how she became a shadow of her former self.

'Like you're a normal person and then it's like... Because I was always a happy-go-lucky, always laughing, joking, and it really did change my life. I became very unhappy and unsociable, and depression set in (Phyl).

The women also hide themselves further by becoming reluctant or refusing to inform others of their condition. Many of the women also envisaged others lack of belief in or rejection of, her condition, and this also contributed to her concealment. Another reason for keeping hidden from others for one of the women was due to her own lack of understanding of her condition.

I wouldn't be saying because I didn't know what was wrong. I wouldn't have discussed it with them. I wouldn't have gone out and spoken about it with friend (Alison).

Anna's concealment of her true self was not a result of necessity, as asserted by the other participants, but was an intentional effort to build a wall or barrier to separate herself from others. Anna viewed herself as different from the others as a result of BMS, and thus felt as though the syndrome could not be understood by someone who did not share her experience.

You can explain the symptoms but unless you feel them and go through them yourself you really can't. I wouldn't be saying it to anyone really (Anna).

### Burning mouth syndrome as an intrusion

The painful symptoms the women experienced as a result of the condition was seen as intruding on their quality of life, their daily routine, and their sense of self. For Alison, BMS intruded on her social life as she felt she had lost a sense of control in this respect.

'Like that now if there was something on I'd be going, how are my going to go out like this. Because, you're even blowing on your tongue. You'd have your tongue sort of out and you'd be blowing on it to cool it down like it's not very nice to going out and doing this you know? I always made up an excuse or give it a miss; I'm not going to go or whatever. So, no (Alison).

BMS also intruded on the women's work life. Phyl detailed her inner struggle as she strove to retain her work/life balance, while the symptoms of BMS obstructed her sense of being in control of her own life events.

I was trying to go to work, but all this was going on in my mouth, the metallic thing'(Phyl).

For Sally and Anna in particular, BMS was asserted to be an intrusive force in many aspects of their life. However, this did not extend to their work. Phyl and Anna both viewed their work as a distraction from their pain and as acting as a barrier to the condition intruding on their sense of self. Ann describes the

'release' that her job affords her but also, interestingly, recognizes the intrusive force of BMS that can easily 'get you.'

Probably the job I have probably makes a difference as well. You have to concentrate very hard on what you're doing. So... my tongue could be on fire while I'm doing it but I don't think about it. And maybe it's the fact that I'm just used to it at this stage as well. It's just there. That's it! Probably if you were at home minding kids all day everyday it would get you much bigger. There would be no forgetting it or release from it. I'm lucky I've the job I've got. (Anna).

Phyl, however, starkly reiterates the intrusion the condition has made on her life. She presents two selves: one that is eager to engage fully in life, and the other self that has been 'brought down' by the intrusive force of BMS. There is an inner struggle as Phyl strives to overcome the obstructive nature of BMS, but is ultimately left defeated as the condition intrudes on her overall sense of well-being and of being in control.

It just made your life so much different. Like, you know when you get up in the morning and you'd say "aw I don't know. I'll do this and I'll do that". It wasn't like that at all. Your day was just so different. You couldn't kind of plan your day, the day before because you just know that the next day you were going to get up and you'd hope that it would be gone but it wasn't, you'd just come down and just kind of potter about. There was really no kind of go. You'd be kind of brought down by it. (Phyl)

This intrusion of Phyl's quality of life also affected her sense of self. BMS affected every aspect of Phyl's life, to the point where there appeared to be no distinction between the self and the condition. The 'self' had become consumed by BMS and she and her condition have become inseparable entities:

Oh, it affects you in every way. Like, you're there all day and it's there all day long. (Phyl).

The intrusive nature of BMS was most poignantly portrayed as a foreign entity that intruded on the women's bodies as well as on their quality of life. Phyl's personification of her symptoms aptly portrays the condition as a foreign body:

And it was actually like somebody... the way it felt was if somebody would get a potato peeler and scrape the top layer off your tongue, and it was raw, and then someone would boil a kettle and pour that down on top of your tongue, and then after that somebody would get a red hot poker. (Phyl)

Phyl, personified her symptoms and described them in vivid detail as being inflicted upon her by a foreign body. This perception was in stark contrast to Anna's view of her condition. Instead of viewing her symptoms as being inflicted upon her, Anna portrayed herself as active in imposing these symptoms upon herself:

'You get this metallic taste sometimes and it's like putting your tongue into a salter, like pure salt (Anna).

For Anna, she had a choice in how her condition affected her, and viewed the self as an active participant in her acceptance and management of her condition.

'You can't let it affect your life. It isn't life threatening, it isn't major, you know. You just do what you have to do. Your tongue will be hanging out but you'll get there in the end (Anna).

Sally expresses her condition as a foreign body over which she has no control. Despite her endeavour to maintain a healthy lifestyle, she is left to feel deserted and forsaken by her body and this has a negative effect on 'self' as independent and autonomous:

I suppose having it, I just wonder with everything that's out there... sometimes I feel, why should you, because I barely drink and I would consider myself a healthy enough eater and I would try and do things the right way and yet I've ended up with something and I do say well "why me?" when I 'm supposed to be doing the right things, when I see people who are out partying every night and falling into work half-drunk sometimes and nothing happens, and I sort of question that (Sally).

Alison, mirrors Sally's conception of her symptoms as a foreign entity and feels as though her own body has become foreign to her. However, in contrast to Phyl, Mary describes her body in more sympathetic terms, suggesting that she is striving to accept and understand this mysterious condition:

My body was trying to deal with so much and with everything going on inside it (Alison).

Mary further considers her condition with a fresh perspective. She maintains that she has regained control of her body and is ready to take ownership of her condition, so much so that it now forms part of her identity.

Now I go out and feel much better and so, ya, definitely. And you learn to live with it, like it's my illness, I suppose (Alison).

### Diagnosis as a turning point

Diagnosis provided a turning point for each of the women in that it marked a process of managing and treating BMS. All of the women communicated considerable relief at finally being diagnosed and expressed relief that their pain and discomfort was legitimized. Diagnosis represented a release of the struggles they had endured and a 'letting go' of tensions. The 'self' was acknowledged and participants viewed their diagnosis as significant progress in managing their condition and in living fully.

For Phyl and Anna, diagnosis represented an awakening, a 'coming around' from which stemmed a fresh perspective of their condition, and rationalized their thoughts concerning BMS. Their pain and suffering was validated and enabled the 'self' to cope.

But this was up until Dr. Sarah told me, and then after that you get the medication and you start coming around and telling yourself "it's only BMS" (Phyl).

I was just glad myself that there was such a thing, like for me that this thing actually does exist and you have it (Anna).

Diagnosis also aided understanding of the condition and resulted in adoption of accommodating behaviors. These behaviors were characterized by strict routines and strategies that the women abided by, resulting in 'self' becoming more in control of the condition.

But as you go along the line, the when you get diagnosed, you start changing your food. You wouldn't eat anything very hot, like if you got a soup you'd let that cool down you wouldn't eat it because some, most of the time you'd say "oh god, I'm starving. I'll have it"; but you wouldn't (Phyl).

Diagnosis symbolized a retrieval of the former self that had been lost to BMS. When asked about the effects of diagnosis, participants conveyed a renewed, more autonomous self that was in stark contrast to the 'self' awaiting diagnosis. This was portrayed by Phyl as a re-birth that promised hope for the future, while Alison described the freedom of being able to socialize again:

I like to get up now and get through the day. It's brilliant. It's like a new lease of life really. It's so different now, it's just so different. If I could draw a picture you know. It is, it's just so different... This is the change now in my life. This is where, this the direction I'll be going in now. I knew then that there was hope out there and that things will change for the better (Phyl). The metaphor of a journey to describe the process of being diagnosed was expressed by the majority of women. It was evident that the women were at differing stages of this journey. Phyl, Alison and Anna viewed diagnosis as the end of a journey characterized by uncertainty and struggle and viewed the acknowledgment of self that diagnosis provided as the end destination. For Sally, however, diagnosis signified the beginning of a journey in managing the self and her condition. She viewed the self as an active participant in the journey and that only through her perseverance could she reach her destination of managing the self.

I might just have to get on with it, and then maybe sometime I will find out, some day. If I just keep going and try different things, I might eventually get there (Sally).

Many of the participants acknowledged diagnosis as being crucial in coping with the condition and spoke of the negative consequences of not being appropriately diagnosed. Failure to be diagnosed was articulated as potentially damaging to mental health and to the affirmation of the self. Both Sally and Phyl acknowledged the significance of early diagnosis:

If more dentists and doctors knew, they wouldn't have to wait as long and therefore depression might not set in. Do you understand? (Phyl).

But the fact that I knew myself slightly about it helped, whereas it could be somebody else who doesn't know, and they could end up having a nervous breakdown thinking that it is all

their head, because you will read a lot of it on the internet where it says that some doctors do believe that it is all in their head, that it's not actually there at all. And when you read that then you do sort of think "oh god, I am cracking up". It is something that's in my head and it's not really there (Sally).

### Discussion

This IPA study provides further insight into adult females' experience of what it is like to live with BMS. As each individual's life situation differs, so too does each person's personal experience of chronic illness [36]. Four master themes were identified in the data: doubting self; hidden self; BMS as an intrusion; and diagnosis as a turning point. The themes elaborated on the women's experience of living with BMS, and how one understands and constructs the 'self' in order to deal with the daily physical and mental challenges of BMS.

All the women identified with a diminished sense of 'self' as a result of BMS, which negatively impacted on their enjoyment of everyday life and their psychological well-being. This diminishing effect on 'self' resulted in a period of doubting and questioning themselves, or engaged in a process of rumination. This negative excessive mulling over of the origin of their symptoms and its negative effect on their lives led to a negative emotional state, or for some pinpointed the onset of depression. This depressive state was exacerbated by the women's concealment of their true or whole self.

The women failed to disclose their symptoms for fear of disbelief, and lack of understanding from others, and they became increasingly withdrawn. They acknowledged this transformation as a loss of former 'self' where they engaged in a process of mourning for this former self. Williams [37] also recognized a loss of 'self' among chronic pain sufferers. His study with a population suffering from arthritis identified a loss of a former self and the resulting confusion of personal identity. Participants of the present study demonstrated this confusion of identity, where 'self' became concealed and participants described their confusion as they struggled to retrieve any remnant of their former selves. The extent to which their sense of 'self' was affected varied across participants, with Phyl, in particular, expressing a distinct lessening of her sense of self. In contrast, Anna presented the 'self' as virtually unaffected by BMS. This suggests that individual differences, including variances in personality, may determine patterns of coping over time in the acceptance and management of this medical condition.

BMS was also expressed as an intrusive force that disturbed the women's life world. BMS was perceived as a foreign body invading their well-being and their quality of life and transforming them from being 'independent' to being 'victims' of their symptoms. Their desire to socialise faded and they suffered from living restricted lives where 'self' was struggling to remain in control. The conception of BMS as a foreign body was one of the more striking images that emerged from the study. One of the women

in particular felt as though her body had deserted her, despite her endeavor to maintain and enhance her health. This resulted in feelings of frustration and a feeling that 'self' was not independent or autonomous. This is in contrast to Koninger et al. [38] large-scale study of chronic pain after hernia repair, where none of their participants reported feeling that their body was foreign to them as conveyed by one of the questions in the study's questionnaire. The foreign body concept, however, was also interpreted to articulate participants' sense of control in this study.

Diagnosis was seen as transforming, or retrieving, 'self' that was lost prior to medical confirmation of the syndrome. Each of the women communicated relief at being finally diagnosed and felt that their suffering was finally validated. The women also asserted that diagnosis gave them an increased sense of control over their condition. The loss of 'self' as a result of chronic illness is consistent with Charmaz's [39] concept that the former 'self' deteriorates without the development of a valuable new 'self'. This result in the individual's suffering from restricted lives, social isolation, being discredited and fear of burdening others with their pain. In particular, this study observed women's suffering from restricted lives. This was evident throughout the study and was perhaps most poignantly emphasized by the conception of BMS as an intrusive force that dictated day-to-day living and lessened their enjoyment of life. Through the process of diagnosis, the women's locus of control moved from an external to an internal focus. This finding is in accordance with Aldrich & Eccleston[40] study that highlighted the significance of whether one has control over one's pain, or whether this pain is being used to control and change the person. One of the women in particular illustrated how the sense of control that diagnosis gave her helped her to retrieve 'self' that was lost to BMS. She described herself as being 'freer' and 'active' in the management of her condition.

In terms of the study's limitations, it was recognized that participants were drawn from only a small cohort of patients attending one BMS clinic. However, it provides a rich understanding of the experiences of women diagnosed with BMS, since little is known about the subjective experiences of the syndrome and its impact on individuals' quality of life. The first-hand accounts of the experiences of these patients allows for a description of the effects of BMS, which could not be captured through a quantitative method. The themes highlight the challenge patients' face on a day-to-day basis and the idiosyncratic effect of the syndrome on their quality of life.

In conclusion, the findings of this study reveal that BMS affects the women's sense of self over time and has a negative impact on their quality of life. The 'self' is changed from being independent, dynamic and autonomous to a fragmented 'self', devoid of the attributes of the former self. This is consistent with the results of Smith & Osborn [34,35] and their exploration of the negative debilitating impact among those with benign lower back pain. In their study the self-concept had deteriorated due to assaults in the form of adverse experiences and in its place a new 'self with

pain' was presented. The debilitating effect on the 'self' as a result of BMS may indicate that individuals with this medical condition may benefit from psychological counseling, as BMS has a major impact on an individual's life experience.

Diagnosis, acceptance, and management of the condition appear to reclaim the true identity and sense of 'self'; and further research should focus on these three domains. This may improve patients' perception of their control over BMS and may facilitate a healthier recognition of the syndrome.

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